Lessons Learned From AHRQ's State and Regional Demonstrations in Health Information Technology

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Chapter 1. Introduction

In 2004 and 2005, the Agency for Healthcare Research and Quality (AHRQ) Health Information Technology (Health IT) portfolio invested over $166 million in grants and contracts for planning, implementing, and evaluating the impact of various information technologies on the quality, safety, and efficiency of health care delivery. Among these initiatives were the State and Regional Demonstrations in Health IT (SRDs), which were each awarded $5 million contracts to support State- and regional-level health information exchange (HIE). Five contracts began in October 2004 in Colorado, Indiana, Rhode Island, Tennessee, and Utah, and a sixth began in Delaware in October 2005. This report describes the cumulative lessons learned across the six contracts (hereafter referred to as the SRDs) and their 5 years of experience.

At the time these demonstration projects were funded (2004-05), there was a limited amount of experience with regional or State efforts in HIE. Community health information networks (CHINs), which relied on centralized information databases, had been explored in the 1990s but were not sustained.[1] The eHealth Initiative's Annual Survey of State, Regional, and Community-Based HIEs found only nine operational HIEs (defined as transmitting health-related information among health care organizations and having a sustainable business model) in 2004 and 25 operational HIEs in 2005, and those varied in scope and size.[2] Among those were the Santa Barbara County Care Data Exchange, which started planning in 1998 and succeeded in providing clinical data to health care providers but had closed down by December 2006 because of the lack of value to key funders and participants.[3] Thus, at the time of the SRDs' inception, few other HIE initiatives existed, and policymakers and the SRDs themselves had only a nascent understanding of what it would take to create sustainable, functional, consumer-oriented HIE.

In funding the SRDs, AHRQ intended to demonstrate the provider-, organization-, and community-level effects of HIE on patient safety and quality of care. To that end, the SRDs involved a broad range of stakeholders, including hospitals, ambulatory providers, payers, laboratories, public health agencies, long-term care facilities, and consumers, and conducted their work over a geographically broad area.

The SRDs broke ground in areas of collaborative governance and policymaking for HIE, design of technical solutions to meet community needs, exploring financial sustainability models, and identifying evaluation measures of their efforts. Emerging HIE efforts and newly established health information organizations (HIOs) will face a different policy and financial context in 2010 than the SRDs did 6 years earlier. (This report uses the terms HIE and HIO as defined in the report Defining Key Health Information Technology Terms.[4]) However, the lessons learned and documented in this report are a critical contribution to the rapidly growing literature about HIOs.[5-8] First, this report provides qualitative descriptions of challenges the SRDs faced and the strategies they developed for overcoming challenges. Second, the examples from the SRDs demonstrate the variation in the issues that each SRD confronted based on its local context. Third, the appendixes to this report provide some summary guidance based on the lessons learned. Appendix A provides a guide to costs in starting up and operating an HIO that has been developed based on the experience of all SRDs. Appendix B lists policies that the SRDs found to be critical for advancing their HIE initiatives.

Chapter 2. Purpose and Methods

Purpose and Scope

The purpose of this report is to provide an overview of the lessons SRDs learned as they worked to develop State and regional HIE. The information contained in this report is necessarily specific to the SRDs, but it will also be applicable to a wide range of stakeholders interested in HIE and the development of HIOs.

Methods

The information in this report was compiled from a variety of sources over a 5-year period. The following list describes these sources in greater detail.

1. **Monthly teleconference calls and associated meeting minutes.** All of the SRDs participated in monthly teleconference calls between 2005 and 2009. The meeting minutes from these calls were reviewed for lessons learned to include in this report.
2. **Summaries from biannual in-person meetings.** The SRDs met every 6 months to share their experiences on a variety of issues and reflect on key lessons learned. The meeting summaries were also used as a source of information for this report.
3. **SRDs' written deliverables.** The SRDs' deliverables to AHRQ (e.g., monthly reports) provided additional context for the synthesis of the lessons learned.
4. **Other reports and summaries documenting the SRDs' experiences.** These reports include: Report of the SRD Meeting on Lab Exchange, December 2006; AHRQ Meeting Summary, January 2008; Delaware Meeting Summary, July 2008; Lessons Learned Teleconference Summary, November 2008; Denver Meeting Summary, February 2009; and Liability Insurance Report, June 2009 (including interview summaries).[9]

The information from these sources was synthesized and organized into six major categories: stakeholder engagement, governance, finance, technical infrastructure, business and technical operations, and legal/policy. These categories reflect the structure that the Office of the National Coordinator for Health IT (ONC) used for its recent cooperative agreements for State-level HIE, with the inclusion of stakeholder engagement as a separate category in this report. This structure was selected to support consistency across Federal initiatives and offer guidance to new HIOs and other interested stakeholders.

Report Limitations

This report has several limitations related to the timing and structure of the SRD contracts and the data collection methods. First, the SRDs began work in 2004 and 2005. Since that time, significant changes have occurred in the legal, technical, and policy environments, including the passage of the American Recovery and Reinvestment Act (ARRA). ARRA includes millions of dollars in funding for health IT and HIE activities, updates the Privacy and Security Rules of the Health Insurance Portability and Accountability Act of 1996 (HIPAA), and creates new leadership bodies to oversee health IT and HIE activities at the Federal level. In addition, technology has progressed substantially since 2004. Despite the changes in the technical and

policy environments, the lessons learned from the SRDs are still broadly applicable to other HIOs and HIE initiatives.

The SRDs also had access to a steady source of funding for the first 5 years of their existence. This level of predictable support may not be available to new HIOs. Finally, this report presents a broad look at the lessons learned across the SRDs. Additional work to examine these issues in more depth is ongoing, with the results expected to be published by AHRQ in late 2010.

Brief Description of Each SRD

To frame the discussion of the lessons SRDs learned, a description of each SRD and its scope is provided below.

Colorado Regional Health Information Organization (CORHIO). CORHIO is a nonprofit organization aimed at building a prototype data exchange among its four partners: Denver Health, Kaiser Permanente of Colorado, The Children's Hospital, and University of Colorado Hospital. The project uses an enterprise Master Patient Index (eMPI) from which records can be matched and shared at the point of care. CORHIO and its partners went live with the demonstration on December 1, 2008. This system offered authorized emergency department (ED) practitioners at the four sites access to the most common radiology reports, laboratory results, prescribed and dispensed medication information, registration information, and problem lists aggregated from all sites.

Delaware Health Information Network (DHIN). DHIN was created by an act of the Delaware General Assembly and signed into law in 1997 to advance the creation of a statewide health information and electronic data interchange network for public and private use. Partners include consumers, physicians, hospitals, businesses, payers, and reference laboratories.[10] DHIN went live on May 1, 2007, becoming the first operational statewide clinical health information exchange. As of February 2010, DHIN had 160 physician practices connected to the system (1,305 physicians and more than 2,400 total users). The three DHIN-participating hospital systems and LabCorp, Quest Diagnostics, and Doctors Pathology Services provide more than 85 percent of laboratory tests and 81 percent of hospital admissions performed in the State of Delaware.

Indiana Network for Patient Care (INPC). The INPC was created by the Regenstrief Institute in 1994 with the goal of providing clinical information at the point of care for the treatment of patients in the ED. Today, it is a 15-year-old health information exchange with over 40 geographically separate hospitals. Other participants include ambulatory practices, public health departments, payers, laboratories, and imaging facilities distributed across Indiana, including the Indianapolis metropolitan area and Lafayette and Evansville areas. INPC includes records for over 10.5 million patients, such as patient registration data for ED visits, inpatient and outpatient hospital encounters, and ambulatory care visits; clinical data such as laboratory results and immunizations; and free-text notes, including diagnostic studies, procedure results, operative notes, discharge summaries, and radiology images. The information in the INPC follows the patient, not the physician or a specific health system, so physicians can view a patient's previous care information from all participating institutions as a single virtual record. The INPC serves as the backbone for a number of HIE services provided in Indiana by the Indiana Health Information Exchange.

MidSouth eHealth Alliance (MSeHA). MSeHA is a nonprofit that works closely with Vanderbilt University in Tennessee. MSeHA's goal is to implement and evaluate a regional data-

sharing and interoperability service that connects health care entities in the Greater Memphis area. MSeHA began exchanging data on May 23, 2006. As of December 2008, data from 14 hospitals (inpatient, outpatient, and EDs) as well as 14 primary care safety-net clinics and the University of Tennessee Medical Group, representing over 400 providers, were available to 14 EDs, 14 primary care clinics, and hospitalists. The data include laboratory results, diagnostic imaging reports, cardiac study reports, discharge summaries, dictated ED notes, operative notes, history and physical exams, diagnostic codes, patient demographics and other identification, and encounter data. In November 2009, the MSeHA exchange held over 5 million encounter visits.

Rhode Island Department of Health (RI DOH)—current*care*. The Rhode Island Department of Health (RI DOH) applied for and received the SRD contract from AHRQ on behalf of stakeholders across the State and the Rhode Island Quality Institute (RIQI). The project governance has been led by RIQI, which became the State-designated HIO in 2008 and which will receive contractual and operational responsibility for the statewide exchange, known as current*care*, in September 2010. The project's goals are to design, develop, test, deploy, and evaluate an initial health information network (current*care*) to support the secure and reliable exchange of health information, beginning with laboratory results and possibly medication history information. The system is envisioned to include additional types of health data and interfaces with electronic health record (EHR) systems and, when scaled, will be an interconnected statewide health information exchange network that uses a master patient index (MPI) to create longitudinal patient health records from disparate data sources. Data exchange partners will include hospitals, laboratories, EDs, radiology centers, long-term care facilities, other providers, and RI DOH in its role as Rhode Island's public health agency.

Utah Health Information Network (UHIN). UHIN is a nonprofit whose partners include physicians, hospitals, laboratories, payers, local health departments, and health centers. UHIN's goal is to implement statewide information and communication technologies to enable easy exchange of clinical data among members. UHIN is supporting the use of a modest electronic medical record (EMR), commonly referred to as "EMR lite," an MPI, and virtual health records query functionality. UHIN seeks to create provider-to-provider, provider-to-public health agencies, and provider-to-payer messaging through a hub model. To date, UHIN has exchanged administrative data and has begun rollout of its clinical HIE.

Table 1 provides summary information on each SRD, including the name of the project that developed through the SRD contract, the principal investigator, funding sources, and a link to the organization's Web site.

Table 1. Summary information on each SRD

Project name	Supplemental funding sources	AHRQ SRD project principal investigator	Web site
Colorado Regional Health Information Organization (CORHIO)	The Colorado Health Foundation (TCHF) Office of the National Coordinator for Health IT[1]	Arthur Davidson, M.D., M.S.P.H.	http://www.corhio.org
Delaware Health Information Network (DHIN)	State of Delaware Private sector	Gina Perez, M.P.A.	http://www.dhin.org
MidSouth eHealth Alliance (MSeHA)	State of Tennessee Vanderbilt University (in kind)	Mark Frisse, M.D., M.B.A., M.Sc.	http://www.midsoutheha.org
Indiana Network for Patient Care (INPC)	Foundation for eHealth Initiative National Library of Medicine Grant	Marc Overhage, M.D., Ph.D.	http://www.regenstrief.org/medinformatics/inpc/
currentcare (Rhode Island)	Robert Wood Johnson Foundation Information Links Grant Office of the National Coordinator for Health IT[1] CMS Medicaid Transformation Grant State of Rhode Island (in kind)	Amy Zimmerman, M.P.H.	http://www.currentcareri.org
Utah Health Information Network (UHIN)	Utah Department of Health UHIN (in kind)	Jan Root, Ph.D.	http://www.uhin.org

[1]Contracts for privacy and security solutions for interoperable health information exchange and health information security and privacy collaboration.

AHRQ=Agency for Healthcare Research and Quality. CMS=Centers for Medicare & Medicaid Services. IT=information technology. SRD=State and Regional Demonstration in Health Information Technology.

Chapter 3. Lessons Learned

Each SRD had a different foundation of technical and organizational experience with which to build State or regional HIE. Furthermore, each SRD took an individual approach to developing an HIO to facilitate HIE in its State, which is reflected in the varied objectives and technical, business, and governance models. As a result, the SRDs emphasized different lessons learned according to the aspects of HIE in which they became most involved. The lessons learned described below synthesize the reflections of the SRDs for the period 2005-09.

These lessons learned are organized into six categories: stakeholder engagement, governance, finance, technical infrastructure, business and technical operations, and legal/policy. Within these areas, a set of summary statements of the lesson learned is provided. Each summary statement is designed to identify key success factors for the SRDs. That statement is then supported with an example from one or more of the SRDs. The appendixes to this report provide greater detail on specific lessons learned in terms of costs and policies.

Stakeholder Engagement

The SRDs emphasized several lessons learned that highlight the importance of stakeholder engagement in HIE development. The examples provided in this section illustrate the challenges and opportunities in advancing HIE in the face of local stakeholders' concerns, which can include privacy and security of personal health information, the possible loss of competitive advantage, lack of empirical evidence of clinical benefits and value of investing in the HIE effort; these have been reported as barriers to HIE elsewhere as well.[11] The following lessons learned on stakeholders highlight some strategies for overcoming these concerns early in the development of HIE.

Engage a broad range of stakeholders. Each SRD recruited an advisory group of diverse stakeholders from the State or region, including consumers, physician practices, hospitals, health systems, insurers, health plans, laboratories, pharmacies, employers, public health agencies, long-term care facilities, and local government agencies. MSeHA found it particularly important to involve the major employers in their region. Others highlighted the value of engaging safety-net and ambulatory providers on any advisory group. By engaging a diverse set of stakeholders as advisors, the SRDs were informed by a balanced set of perspectives and could develop greater investment within their communities.

For example, through these advisory groups and other efforts, the SRDs tried to build a strong sense of ownership for developing HIE, using a variety of approaches. Most of the SRDs focused on establishing a broad-based multistakeholder board of directors to gain community interest and buy-in. In Rhode Island, RIQI hired a public relations firm to engage consumers, manage communication, and stimulate stakeholder involvement. Word-of-mouth and positive peer pressure were also viewed as effective strategies for encouraging participation within stakeholder groups in HIE activities; when individuals or organizations knew that their peers were participating, they were more likely to join.

Provide a convincing argument as to why potential stakeholders should invest time and money in the HIO. SRDs found that they were more successful in engaging stakeholders when they could articulate the value proposition for HIE for different stakeholders early in the development process. To understand what outcomes stakeholders would consider worth their

investment in HIE, some of the SRDs conducted stakeholder focus groups. From the focus groups, for example, SRDs learned the high value to various stakeholders of exchanging laboratory results (even from national laboratory chains, like Quest and Labcorp). In investigating the value of HIE for nationwide laboratories, one SRD found that these nationwide laboratories are more likely to participate if the HIE becomes the official delivery mechanism for a laboratory or "report of record." The "report of record" is a service-level agreement where a vendor (HIO) meets certain requirements to be an official delivery mechanism for a laboratory. The value proposition for hospitals was reported as the impact of HIE on hospital admissions, ED lengths of stay, duplicative laboratories, ED efficiency, and clinical outcomes. Additionally, when the HIO provides clinical messaging, the hospitals and laboratories alike benefit from eliminating paper-based results processing and maintaining point-to-point interfaces with physician EHRs. By understanding the value for each stakeholder group, the SRDs benefited from stakeholders' increased investment in volunteer time and financial contributions.

Understand the requirements of community consensus. The process of convening stakeholders and building consensus takes a considerable amount of time, and the SRDs warn not to underestimate the time it takes. Many SRDs found that broad community input and consensus take at least 1 year. In Rhode Island, engaging stakeholders in a consensus-driven process was a fundamental guiding principle that resulted in an 18-month process to reach consensus on the authorization policy and technical model for the HIE system. Additional confidentiality protections for the envisioned system were sought through the legislative process and were enacted into law as the Rhode Island Health Information Exchange Act of 2008.[12] Although the consensus process used in Rhode Island may have been more indepth than the process other SRDs used, it demonstrates the time and effort required to achieve consensus across a broad range of clinical, technical, administrative, and consumer stakeholders.

In addition, the SRDs found that they needed to guide the consensus-making process *among* and also *within* stakeholder organizations. For example, UHIN learned that representatives from administrative or billing departments did not necessarily represent the clinical interests of their organization.

Guiding the consensus process requires strong leadership, a clear vision, and substantial in-kind and financial support. Given the need for buy-in from a large number of organizations and individuals, appropriate time and resources must be directed toward consensus-building processes.

Foster ongoing dialog among stakeholders. Ongoing dialog among stakeholders facilitated the development of trusting relationships, which proved necessary for drafting, gaining consensus about, and signing of master data-sharing documents and other legal agreements. SRDs were more successful when they addressed any real or perceived competing organizational interests among stakeholders involved in HIO governance. For example, one SRD observed a conflict between their stakeholders' own sense of what is best from a competitive perspective and what may be best for increasing the overall quality of patient care in the community. SRDs also needed to resolve competing demands from funders and other stakeholders. For example, in developing their business strategy, CORHIO realized they had to resolve a perceived conflict between their board's goal to achieve financial sustainability for the HIO and the stated objective of the AHRQ SRD contract, to use HIE to improve health care quality.

Governance

This section outlines the SRDs' lessons learned about setting up a governance structure for the HIO, including activities such as establishing a board of directors and advisory group, and creating committees where stakeholders may volunteer their time to provide input on key HIO issues. The category of governance spans informal and formal activities that ensure that an HIO is successful in achieving buy-in and use of HIE.

Realize that a board of directors is vital to an HIO's governance structure. A board of directors generally sets strategy, secures funding, and provides oversight. The HIO board should have a strong sense of ownership over the HIO early on. The SRDs found that the following factors are important for establishing a successful board: balanced stakeholder representation, a sufficient number of board members that does not impede the organization's ability to reach consensus, senior leadership with necessary skills and experience to execute the goals of the HIO, and flexibility in board composition and the roles of its members over time.

Establish an advisory board or advisory committees in addition to a board of directors. Because the board of directors is limited in size and probably will not address the needs and issues of all stakeholders, establishing one or more formal advisory group(s) is recommended to represent the employers, payers, and health care community to the board of directors. For example, both DHIN and RIQI established consumer advisory committees to provide expertise, insight, and policy direction to the HIO; as a side benefit, these members also served as champions for HIE in their respective communities. In addition, RIQI established similar groups to address legal, policy, technical, and provider issues. Further, a board-level committee was formed at RIQI to specifically address issues around HIO oversight. The structure of advisory groups will vary depending on the scope of the HIE and whether it is a State or a regional/local initiative. Advisory boards or committees are useful in broadening stakeholder representation and can also cultivate future members of the HIO's board of directors.

Engage volunteers in developing the HIO. The in-kind contributions of the community participants on these advisory groups are necessary, and the HIO should effectively leverage their expertise. Nevertheless, based on their experience, the SRDs warned against overextending these volunteers. In addition, overreliance on volunteers may signal that the business plan needs to be revisited. Volunteers' time and experience can be maximized by providing a clear scope of work for volunteers and defining expectations for outcomes or deliverables.

Allow governance structures to evolve over time. As funding sources and organizational priorities change, governance structures may be updated to best serve an HIO. For example, UHIN was an established HIO focused on the exchange of administrative data before receiving the SRD project contract with AHRQ. With the AHRQ funding, UHIN planned to leverage its existing HIE infrastructure to expand services to include the exchange of clinical information. Thus, the UHIN governance structure transitioned to include more clinical and consumer representation. In Rhode Island, the Rhode Island Department of Health served as the principal investigator to the AHRQ contract on behalf of the community, with the understanding that full responsibility for the HIO would ultimately rest with RIQI as a community-based organization. Until a complete transition is made, the RI DOH and RIQI are sharing the functions of an HIO, but the DOH retains contractual responsibilities and legal liability for the HIE system. Once the full responsibility for the HIE system is transitioned to RIQI, the DOH will shift into its regulatory role, as set out in the Rhode Island Health Information Exchange Act of 2008, which was incorporated into Rhode Island's General Laws.[13]

Finance

The SRDs received a significant amount of funding from AHRQ under their SRD contracts, but those funds provided only one part of the overall financial solution for achieving HIE and developing an HIO. The SRDs reported lessons learned in determining how to best finance an HIO and HIE activities. These include developing a business plan, identifying potential funding sources, and planning for long-term financial viability.

Have a sound business plan. The SRDs emphasized the importance of having a sound business plan at the outset of the project. The business plan should carefully delineate the level of funding needed for establishing the HIO and maintaining operations, and the sources for those funds. Federal funding, other initial financial support, and other revenue sources (e.g., membership fees, transaction fees, and program and service fees) should be included in the business plan. Grant funding should not be considered a long-term solution, although it can be very helpful in launching the HIO. The business case for participants, which identifies the value to organizations of participating in the HIO at different levels, will inform the short- and long-term business plan for the HIO as well. The business plan should also incorporate a plan for long-term sustainability.

A working business plan will satisfy the following expectations:

- Completeness—Does the plan contain all key elements (resources, lines of authority, etc.)?
- Level of detail—Is a sufficient level of detail provided—that is, is the plan actionable?
- General feasibility—Is the articulated approach viable? What are additional items for consideration?
- Substance—What were the primary methods used to determine the path to sustainability? Does the plan include tools for measuring sustainability (e.g., return on investment, cost analysis)?

The SRDs found that their business and sustainability plans needed updating throughout their 5-year contracts. For example, as CORHIO neared the end of its 5-year contract, it planned to hire a national consulting firm to conduct a formal analysis of its business plan. Changes in support from Colorado's governor and legislature, a broadening of its participants, and the inclusion of new services required a revision of its plan. Similarly, RIQI engaged a professional services firm to perform a detailed value analysis of HIE and then, after consideration of feasibility, retained the firm to delineate the components of a potential long-term sustainability model for their HIO.

Secure funding early in the planning process. Funding is needed for all of the HIO's activities; a detailed list of potential cost drivers for the HIO is provided in Appendix A. These include costs to purchase and maintain hardware and software, convene stakeholders, set up the governance structure, establish committees and workgroups, develop legal documents and agreements, identify and prioritize transactions to be supported by the HIO, conduct inventories of data sources, and procure the appropriate technical and professional resources to design and deploy an exchange. To raise the necessary initial and ongoing funds, the SRDs engaged a variety of public and private sources, including Federal and State funding sources, private foundations, and health care stakeholders.

Keep participation costs low. Organizations and individuals—either data providers or receivers—are more likely to join an HIE effort if the costs of participation are low. The SRDs identified a number of strategies to lower costs of participation. For example, MSeHA accepts data in whatever format the participant provides (creating a low barrier to participation) and then converts the data to the HIE's messaging and content standards. In addition, it maps some data received from its data exchange participants to the Logical Observation Identifiers Names and Codes (LOINC) standard. The associated costs are accounted for in the sustainability plan and provisions are made to appropriate the necessary funds. As another example, INPC provides incentives for participation (e.g., value-added products/services). Also, DHIN found that its low cost to participate has fostered a growing participant base. DHIN lowered its costs to participants by developing an interface that is flexible and requires a minimum Health Level 7 (HL7) interface feed and by establishing a low-cost contract with its EMR vendors.

Set long-term expectations with HIE beneficiaries to assume financial responsibility. The SRDs found that it was a challenge to encourage organizations and individuals to contribute toward covering the costs of HIE, but in general they set payment rates in proportion to the extent to which various parties benefit from HIE. For example, some SRDs raised revenue by charging stakeholders and providers based on their volume of transactions. Others imposed a per-member-per-month fee on health plans and a subscription fee for certain value-added services (e.g., quality reporting and hosting). These mechanisms are examples of how beneficiaries of the HIE system may assume some responsibility for financing the system over time.

Technical Infrastructure

This section describes the SRDs' lessons learned about the technical infrastructure of their HIE systems, including system architecture, services, and data and exchange standards.

Know that each of the three main models for HIE technical architecture has advantages and disadvantages. A 2009 Health Information and Management Systems Society (HIMSS) report on HIE common practices classified HIE systems into one of three types of architectures: centralized, federated (decentralized), and hybrid.[14] Table 2 describes these architectures.

Table 2. HIE system architectures

Architecture type	Description
Centralized	Patient data are collected and stored in a centralized repository, data warehouse, or other database, with the HIO having full control over the data and the ability to authenticate, authorize, and record transactions among participants.
Federated (decentralized)	Interconnected independent databases allow for data sharing and exchange, and grant users access to the information only when needed.
Hybrid	This architectures incorporates variations of federated and centralized architectures to harness the advantages of both.

HIE=health information exchange. HIO=health information organization.

Source: Health Information Exchanges: Similarities and Differences, HIMSS HIE Common Practices Survey Results White Paper, HIMSS Health Information Exchange, Best Practices Task Force, March 2009.

The SRDs all use a hybrid model. In most cases, each data sender has its own data store, which is federated but often centrally managed. Furthermore, a number of the SRDs report having a central MPI or record locator service (RLS). An MPI is a common medical record number or algorithm that identifies patients across several institutions. (More information is available from the American Health Information Management Association.[15]) An RLS "provides authorized users of a regional health information network with pointers to the location of patient health information across the network nodes, i.e. the clinical data sources…to enable users to access and integrate patient healthcare information from the distributed sources without national patient identifiers or centralized databases."[16] Although a centralized architecture for an HIE system has some benefits, including reliability and time efficiency of retrieving information from one source, there are some concerns about the security and privacy risks related to storing data in a single centralized repository. The SRDs found that by adopting a federated/hybrid architecture, they achieved benefits such as allowing participating provider organizations to maintain control over patient data,and avoiding any concern over the comingling of data across different provider organizations.

Provide services that quickly demonstrate to participants the value of the HIE system. Core services commonly supported by the SRDs include the provision of laboratory results, radiology results, dictation/transcription data, medication lists, and administrative data (e.g., dates of inpatient, outpatient, or ED visits) to participating providers. Many SRDs have used an incremental approach to making HIE services available. Currently, some SRDs are also investigating the feasibility of providing other value-added services, including comprehensive medication histories, patient portals, quality reporting, and medication reconciliation, to increase value for participants.

Use existing and emerging standards and an extensible, scalable platform. The SRDs recommend using standards—common messaging and syntax for exchanging information—to facilitate the exchange of health information. Standards supported by the SRDs in this project include HL7 2.x for messaging; LOINC and SNOMED for laboratories; CPT, ICD-9, and ANSI X12 for administrative transactions; and NCPDP for pharmacy data. As the SRDs discovered, even though numerous standards are available for both data transmission and content, few exchange participants were able to send standardized information. For example, the MSeHA accepts laboratory information in whatever format the data sender can provide and maps this to LOINC. Currently, it supports LOINC mapping for the 50 most common test results in the ED. CORHIO has followed a similar approach; it mapped the top 100 laboratory tests along with the top 25 radiology reports from its four exchange partners to LOINC and SNOMED. The lesson learned is that 100 percent mapping to standard is not required to have useful information available to users.

The SRDs also suggest that HIOs consider using the standards and recommendations of the Health IT Standards Committee. Keeping updated on discussions of national standards is helpful to ensure that HIE initiatives select standards in line with the national trend. MSeHA and CORHIO used the Markle Foundation's Connecting for Health Common Framework and its technical guides[17] and found them to be helpful for understanding core concepts.

Understand that there are issues associated with mapping current standards. A number of the SRDs reported that using LOINC mapping to exchange laboratory results has been laborious and that prioritizing the mapping effort can help reduce this barrier to exchange. (One study found that 80 percent of all laboratory tests would map to 80 codes (2 percent), suggesting that it is possible to prioritize mapping efforts.[18]) Until LOINC is fully implemented, HIOs

should educate technical and clinical professionals about the value and use of LOINC. Furthermore, point-of-care devices are increasingly being used in clinical settings where routine tests (e.g., simple blood chemistries) are done. Many of these results are not LOINC coded, which presents challenges for creating a comprehensive medical record.

Realize that patient identification and matching can be a core challenge for HIE. As an HIE system grows to include more patient records, optimizing patient matching and record location becomes increasingly important. The SRDs tested various methods for patient identity management and record location. Most utilized an MPI for patient identification; they found that, in order to develop an accurate community MPI, their exchange partners had to clean up their local MPIs before loading records into the community MPI. MSeHA did not build an MPI. Algorithms tuned to match patient demographics were used to link records from disparate organizations.

Once an MPI was in place, SRDs differed in the approach they took to patient matching. The SRDs selected a deterministic, probabilistic, or hybrid matching method. In choosing a matching approach, the SRDs had to balance the rate of false positives (records that appear to match when they do not) and false negatives (records that do not appear to match when they should) and the implications for their users. A high rate of false positives can reduce trust in the system, while a high rate of false negatives may deter users from using the system if it means they frequently cannot locate information. As users gain familiarity with and develop trust in the system, the approach to matching may change.

Many SRDs reported that they had to work extensively with their exchange partners to agree on a minimum set of identifiers for patient matching. In addition, the process of fine-tuning the patient matching algorithms and setting thresholds for patient matching that would be acceptable to the community is intensive in time and resources, involving the SRDs' vendors or their in-house technical staff. An indepth discussion of strategies and approaches to matching patients to their medical records is now available.[19]

Know the advantages of buying vs. building HIE software. The SRDs stated that, although building their own HIE software products takes a considerable amount of time, effort, skilled resources, and expense, these products can be customized to the HIO's needs. Readymade HIE software products, however, have recently become more widely available and have the advantage of being installed and implemented relatively quickly. Several SRDs selected commercial off-the-shelf products that they customized to meet their local needs. This customization process can increase the costs of ongoing maintenance. Of the SRDs, three—INPC, MSeHA, and UHIN—started the process with a homegrown/custom system. UHIN started with a custom-built system in partnership with HealthCare Transaction Processors (HTP), which has since been purchased by RelayHealth. UHIN has transitioned to a commercial product (Axolotl) and continues to use RelayHealth's gateway system for some clinical connectivity. MSeHA is currently working with the Informatics Corporation of America (ICA) to transition the MSeHA to ICA's CareAlign system. INPC continues to use its in-house system developed by the Regenstrief Insititute.

Table 3 lists the vendors each SRD used.

Table 3. SRD outsourcing of technical operations and vendors

Name of HIO	Current HIE system vendor
CORHIO	Sun Microsystems
DHIN	Medicity
INPC	In-house system developed at the Regenstrief Institute
MSeHA	Informatics Corporation of America (ICA)
RI DOH/RIQI	EDS [HP][a]/InterSystems
UHIN	Axolotl and RelayHealth[b]

CORHIO=Colorado Regional Health Information Organization. DHIN=Delaware Health Information Network. HIE=health information exchange. HIO=health information organization. INPC=Indiana Network for Patient Care. MSeHA=MidSouth eHealth Alliance. RI DOH=Rhode Island Department of Health. RIQI=Rhode Island Quality Institute. SRD=State and Regional Demonstration in Health Information Technology. UHIN=Utah Health Information Network.

[a]Since RI DOH's initial procurement, EDS has been acquired by Hewlett Packard.

[b]UHIN began by using a custom-built system and subsequently transitioned to a commercial vendor.

Develop a relationship with an HIE system vendor: It is crucial to operations and management. The SRDs that outsourced their technology operations to a vendor were highly dependent on their vendor to complete the major functions of the HIO, such as hardware, software, interface creation and maintenance, and data center. These SRDs agree that when selecting a vendor, it is important to seek both a high-quality software product and a team that will be responsive to HIO needs.

Realize that technical development is influenced by policy and operational considerations. Several steps in HIE system development took more time than the SRDs anticipated, delaying technical development in some cases. The timeline for developing the technical solutions for HIE can be affected by the process of developing policies with considerable stakeholder input, establishing data-sharing agreements, negotiating liability insurance, resolving technical issues involving programming, and differences in readiness of user sites to go live. For example, MSeHA was technically ready to exchange data in January 2006; however, it took until May 2006 to change internal participants' policies for notification, negotiate the data-sharing agreements, write policies, and obtain liability insurance.

Business and Technical Operations

The business and technical operations of an HIO are broad and varied. For example, the SRDs were tasked with addressing the organizational needs of an HIO (e.g., staffing and meeting business goals), managing the actual use of the HIE by stakeholders, and evaluating the impact of the HIO's activities.

Recruit a large user base. The SRDs emphasized the need to consider a wide range and large number of organizations as potential participants to maximize the HIO's user base. A critical mass of data sources and user base must be achieved to obtain buy-in. If there is not enough information in the HIE system, users will not participate because doing so offers only marginal benefits. For example, the SRDs noted the importance of recruiting as many ambulatory care practices as possible because most health care is delivered in ambulatory

settings. Other key partners include hospitals, laboratories, and other entities that can provide data that can be used to populate the system. Large self-funded employers are often highly desired partners because of the large potential user base that they bring (i.e., health care plans and affiliated providers that serve their employees). Similarly, self-funded employers have a lot to gain from the HIO in terms of efficiency because they bear all of their employees' health care costs. The SRDs found that the need for recruitment continues throughout the HIO's life cycle, and the SRDs continue to recruit new participants.

Use creative marketing and recruiting strategies. Along with lowering costs of participation and addressing perceived barriers to participation, the SRDs found creative ways to recruit participants to the HIEs. They marketed areas of potential benefits to payers and employers (e.g., disease management, obesity reduction, improved management of workers' compensation claims). UHIN conducted an analysis of prospective participants' workflow and then worked with them to identify how the HIO could address their workflow needs. UHIN also allowed the use of participants' existing connection to the UHIN gateway to feed the MPI. Hospitals, laboratories, and physicians can encourage others to participate. UHIN found that hospitals, laboratories, and other data sources were more likely to participate in the HIE when their own physicians requested it. The SRDs noted that all participants should have a strong desire to take part in HIE, have resources to dedicate, and maintain a sense of project ownership and commitment.

Demonstrate quick wins. The SRDs sought ways to demonstrate quick wins as an important strategy for building momentum and gaining a critical mass of participants. This frequently involved identifying key areas where they could easily provide participants with valuable information. For example, DHIN indicated that by focusing on clinical messaging and making it available early in the implementation phase, they were able to garner buy-in from providers and demonstrate that the system worked. In the next phase, they focused on patient search functionality, which allowed providers to query 2 years of data stored in DHIN as a result of the clinical messaging phase. Therefore, when the search function was turned on, the majority of Delaware's population had some form of clinical information available for query view via the community MPI and record locator service. This meant that when authorized providers looked up their patient, they were very likely to find clinical history on the patient in the system. With this success, the user adoption of DHIN grew by 250 percent in 6 months. The SRDs caution, however, that the HIOs should set realistic expectations in defining wins and the value for providers.

Identify clinical settings that are expected to have high and rapid impact. Selecting settings and scenarios in which HIE can increase value for providers supports successful recruitment of new HIE participants. RI DOH, for example, chose four target use cases as initial areas to explore for potential evaluation: adult chest pain unit, management of newborn risk for Group B strep and hepatitis B, pediatric emergency care for fever, and care transitions for nursing home patients. Results derived from this exploratory study revealed challenges in evaluating some use cases (e.g., adult chest pain) while confirming the value proposition of the specific features and implementation timing of the RI HIE system for others (e.g., long-term care). Due to other project changes, Rhode Island chose an alternative evaluation strategy, as described later; yet, this process of identifying use cases in which HIE could have a positive impact helped to shape some of the strategy for focusing HIE development.

Reduce barriers to participation. The SRDs use multiple strategies to reduce the real and perceived barriers to participation. A number of the SRDs also worked to identify how

workflows would be impacted and to ensure that participating organizations were well versed on the impact to providers.

The SRDs also found it necessary to foster and develop confidence in privacy and security measures and develop appropriate policies and technologies to ensure that information is appropriately protected. This was often accomplished by educating data senders and users about the HIO and the processes that would be used to secure patient information. To obtain the buy-in of HIO stakeholders, the system must be built to protect consumers' health information, while at the same time addressing the perception of risk to participating organizations with liability and business concerns.

The SRDs also worked to minimize the burden on data providers, as they found that those who hold data are more willing to share information if they are not required to process it before submitting it. To lower the burden, MSeHA agreed to accept information in whatever format the participant was able to offer it and addressed the data processing on the HIO's side.

Finally, the SRDs found that they could develop confidence among users and increase acceptance and adoption by involving stakeholders in user acceptance testing and other testing processes.

Demonstrate the value and function to participants. One of the most effective recruiting strategies was to demonstrate the HIO's function and value. Participants who were initially skeptical of the HIO's ability to be successful were more easily convinced once the HIE system was up and running. Although it was often assumed that HIE participants would pay in accordance with the benefits received, many health care providers and clinicians do not understand the premise of an HIO and are uncomfortable with its pricing model. To address these concerns, the SRDs developed strategies to educate participants about the HIO's function and value. For example, DHIN has added features to its system and plans to develop a patient portal, clinical decision support, and benefit eligibility and claims processing systems. MSeHA counteracted perceptions of the high cost of participation by estimating its costs on a per-citizen-per-year (PCPY) basis and then used its estimate ($2 PCPY) for marketing purposes. To address any negative past experiences with health IT and/or HIE, the SRDs provided careful documentation and information that addressed specific, as well as more general, concerns.

Over time, the services and pricing an HIO offers will likely need to evolve to accommodate users' changing views of value. Therefore, educating stakeholders about the function and value of the HIO will be an ongoing process that evolves over time.

Train providers to prepare them for workflow changes. The SRDs emphasized the importance of assessing the changes in workflow that will result when the HIE system is operational. During the planning stage, careful consideration should be given to minimizing workflow disruptions and ensuring that users are well trained and prepared for changes in workflow. The SRDs caution that the fit of the HIE system into clinical workflow and the training of users are important for promoting ongoing use of the HIE system. If the system is not intuitive and easily integrated into clinical workflows, providers will not use it.

Expect substantial operating costs. Operating costs for an HIO, including legal and intellectual property, liability insurance, policy development, personnel, overhead and indirect costs, data center and hardware, accreditation and certification, marketing and stakeholder management, database setup and maintenance, software, interface creation and maintenance, and training and help desk costs can be significant, and can even exceed the cost of acquiring the HIE system technology and other startup costs. Making estimates and determining a way to cover these operating costs are necessary for building a sound and sustainable model. Appendix A

includes a template of the operational costs commonly incurred by an HIO and can guide other HIOs in forecasting their operating costs.

The SRDs incurred higher operating costs than originally projected. For the HIO to be sustainable, the operating costs must be clearly understood and properly funded. In addition, the cost benefits derived from the HIO may not be realized for several years. This challenge is discussed in greater detail in the following section.

Assume that the cost benefit derived from HIE will not be realized for several years. The cost savings generated from improved efficiencies and health outcomes should not be expected to sustain an HIO for the first several years of operation. MSeHA found that while savings from lower ED expenditures, reduced duplicate laboratory and radiology rates, and lower inpatient admissions may provide some cost offset for the first 5 years, such savings from the ED implementation will not cover the cost of the entire HIE initiative. Also, improved health outcomes from preventive care and treatment of chronic conditions may not lead to reduced costs during the early years of the HIO. For this reason, HIOs should ensure that they have adequate capital to maintain the initiative until the cost benefits begin to accrue.

Set realistic expectations for quality and cost metrics. There are multiple factors to consider when establishing an HIO, including the business, market, and financial aspects, and the potential improvements to the quality and efficiency of health care. One of the challenges in establishing an HIO is that quality improvement may not drive economic sustainability. The SRDs also noted that over time, preparing for a large and growing number of users requires considerable planning and management. They continue to determine how to sustain user participation both operationally and financially.

Realize that needs for liability insurance will vary based on the organizational structure and governance, technical approach, and service offerings. The SRDs noted that obtaining liability insurance was often a protracted and involved process. Hiring a knowledgeable insurance broker was seen as an effective strategy, as was beginning the search for liability coverage well in advance of the planned go-live date. Since HIE is a relatively new endeavor, many insurance brokers and underwriters are not familiar with the process. The SRDs often had to educate brokers and underwriters regarding relevant Federal and State laws and regulations and carefully review policies to ensure that there were no gaps in coverage. Additional information regarding the SRDs' experiences in seeking and obtaining liability coverage and additional lessons learned regarding this process are described in *Liability Coverage for Regional Health Information Organizations: Lessons from AHRQ's State and Regional Demonstrations in Health Information Technology and Other Community Efforts*.[20]

Understand that evaluation of HIE can have multiple goals. The SRDs used evaluation to understand who uses the HIE system, why they use it, and how well the system works for them; to understand the impact of HIE on the clinical environment; and to understand whether the HIE system has an impact on quality and efficiency of care. The SRDs' evaluation plans measure both process and outcomes. The SRDs' evaluation tools and materials include a survey of users, review of data reports, interviews with clinical staff and participating institutions, and usability testing. The SRDs then used their testing and evaluation results to improve their system, substantiate the value they provide, and support quality improvement efforts. At the time of this writing, some SRDs' evaluation activities were still in the early stages of planning and implementation.

Develop evaluation metrics and data collection processes that are applicable across the entire continuum of care. Evaluation metrics should be designed to measure the care across

settings, including inpatient and outpatient settings. In developing the evaluation design, primary and specialty care provider practices and safety-net clinics should also be included. A full evaluation requires the collection of data across the care continuum. Strategies for collecting data include surveys, focus groups, and key informant interviews.

Incorporate flexibility in evaluation approaches. Evaluation activities will likely evolve over the course of the HIO's life cycle. Therefore, the evaluation approach requires flexibility with respect to the timing, planning, resources, and analyses that are conducted. Depending on the scope and type of the evaluation selected, an organization may need to seek approval from its institutional review board or from the Office of Management and Budget (OMB) (for federally funded data collection efforts). These processes, particularly OMB clearance, can be quite lengthy. Another consideration is that the operational rollout plan may or may not support data collection for the evaluation (e.g., if the rollout is done quickly, "pre" data may be difficult to collect for some studies). It was suggested that evaluation activities be integrated into the project as early in the process as possible.

Approaches should account for the long and evolving establishment of an HIO. Many SRDs experienced delays in the deployment of the HIE system, which compressed the timeline for evaluation. The data they had originally anticipated were not always available. As RI DOH found, the requirement for consumer enrollment and authorization prior to allowing data to flow to the HIE system means a slower accumulation of data in the HIE, which in turn limits the data available for evaluation of system-generated and user-focused measures during the contract period. RI DOH has shifted its evaluation focus to include consumer enrollment in the HIE system (who, how many, correlations with utilization, etc.), policy drivers for system development and the role of the State in the HIE system.

Legal and Policy

The legal and policy issues associated with developing HIE on a State or regional level include setting up the legal structure of an HIO and the policies that guide the technical development and operations of an HIE system. Just as the technology for electronic HIE evolved differently for each SRD—based on their original goals, types of data, and data-sharing partners—so too did their policies. The SRDs found that strong dependencies exist between policy and technology development, and many of the lessons learned described in the following sections emphasize the need to begin policy development early on, in order to reflect community and stakeholder requirements and relevant law and regulations, and to inform technology development. Appendix B provides a list of policies to consider.

Know the options for an HIO's legal structure. Many SRDs chose to incorporate their HIOs as nonprofit organizations, which required them to identify their organizations' community benefit if they pursued 501(c)(3) Internal Revenue Service tax-exempt status. DHIN was created by an act of the Delaware State legislature and is considered a public-private partnership. As a public instrumentality of the State, DHIN enjoys sovereign immunity, and the enabling legislation offers its participating providers liability protections. In Rhode Island, the State legislature did not establish the HIO as a public utility or public-private partnership, but it did offer access to repayable bonds to help fund HIO operations to a State-designated HIO that was named from a competitive bid process. This mechanism was established by the State legislature through a 2006 budget article, which provided RIQI (which was selected from the competitive bid process as the State-designated HIO) an opportunity to receive support from health insurers

and the State (as a self-insured employer and through the Medicaid program) if certain conditions were met. (Ultimately, this mechanism was not utilized in favor of direct stakeholder contributions and continued pursuit of a long-term funding strategy.) In sum, legal status can be influenced by how an HIO originated and can have financial implications.

Realize that Federal law and regulation can impact HIO policies. Although few Federal or State regulations are specifically written for an HIO or an HIE system, Federal laws and regulations can impact the exchange of health information. For example, the rules governing when written patient permission is required for the disclosure of protected health information (PHI) are set forth in the HIPAA Privacy Rule and expanded under ARRA. They apply to health plans, health care providers, health care clearinghouses, and now under ARRA, their business associates (including HIOs). Federal regulations developed under the Clinical Laboratory Improvement Amendments (CLIA) provide that laboratory "test results must be released only to authorized persons and, if applicable, the individual responsible for using the test results and the laboratory that initially requested the test." CLIA allows States to define "authorized person" in their laws, which could have an impact on how laboratory test result information is disclosed. Another example of how law may apply only to certain types of information is the Family Educational Rights and Privacy Act (FERPA), which applies to school health records and requires parental or student permission for disclosure of school health record information, with the exception of health and safety emergencies. The confidentiality of alcohol and drug abuse patient records from specific treatment facilities receiving Federal funding are regulated by 42 Code of Federal Regulations (CFR) Part 2. After reviewing and discussing 42 CFR Part 2, one SRD decided at the outset to exclude specific types of organizations as data sources for this information from their HIE. More information on these Federal and State laws and regulations is available from the 2007 report for the Office of the National Coordinator for Health IT titled *Privacy and Security Solutions for Interoperable Health Information Exchange: Nationwide Summary*.[21]

Know that State laws and regulations can impact HIO policies. Some State laws more stringently restrict the disclosure of health information, or certain types of health information, than would be permitted under HIPAA alone. For example, a law requiring patient authorization for the specific disclosure of health information for treatment purposes would be more stringent than HIPAA. HIOs in some States may need to develop policies different from HIOs in neighboring States due to differences in each State's laws governing the confidentiality and uses of health information. For example, a review of State mental health law prompted Rhode Island to adopt a definition of disclosure that requires patient authorization to be obtained prior to data leaving the original source for transmission to the HIE system; this legal interpretation is a key driver of Rhode Island's HIE system authorization policy and the technical solution that supports it. In Delaware, DHIN promulgated regulations that give authorization to laboratories to release to DHIN all data for patients and providers in Delaware.

Understand stakeholder requirements for HIO policies. Law and regulation may put some boundaries around possible direction for HIE policy development but are not the only factors to consider. For example, one SRD found that policies regarding health information exchange that would be permitted under law did not always meet consumers' or users' requirements for how health information should be treated in an exchange. Furthermore, through the process of involving other stakeholders in HIE development, the SRDs found that the interests and focus of advocacy organizations, individual consumers, and providers (as potential users of an HIE system) can conflict with one another and be difficult to resolve. HIE policy

development will likely be shaped by compromise across competing views, within the context set forth by Federal and State law.

Know that options for patient authorization policy (to disclose/exchange health information for treatment purposes) vary. Patient authorization (or permission) policies are often positioned along a spectrum that is colloquially referred to as ranging between opt-out and opt-in, and policies usually fall somewhere between the two poles. An opt-out policy, which does not require patient authorization to disclose or exchange health information, allows PHI to be automatically included in the HIE system unless the patient requests otherwise. Under an opt-in policy, a consumer must actively authorize the disclosure of health information through an HIE system. Each model for patient authorization policy has different implications for technical and business operations, and the model chosen by each of the SRDs was largely driven by the SRD's individual community—the stakeholders involved, the legal context, existing business practices, etc. Most SRDs adopted an opt-out policy. In Rhode Island, a type of opt-in policy was adopted under which consumers must affirm their intent to participate in the HIE system and explicitly authorize the desired level of access to their health information by providers.

Anticipate that policies and procedures will impact technical and business operations. The SRDs advise that comprehensive policies be developed early on in the planning process for HIE, then updated based on the lessons learned during the demonstration period and as HIE matures. For example, Rhode Island's HIE stakeholders developed a specific patient authorization policy, which required authorization from patients to allow PHI to (1) be transmitted to the HIE system and (2) be viewed by treating providers. As a result, additional technology development was required to support a two-stage authorization process that was not available in an off-the-shelf solution, and Rhode Island worked very closely with its vendor to meet stakeholders' expectations for policy implementation. As a different example of operations affecting policies, MSeHA found that having a strong auditing system can inform and support data-use policies.

Sequence policy development carefully. Some policies and procedures should be completed during the planning phase for HIE, others prior to go-live, and others can be completed in the post-go-live phase. A number of SRDs experienced delays in their go-live dates because critical policies or procedures had not yet been finalized.

Chapter 4. Conclusions

The lessons learned compiled in this report are summarized from specific examples of the SRDs' experiences, but also reflect similar themes and recommendations that others have observed from efforts to develop HIE systems and HIOs in their communities.[22-25] The SRDs found that, important as the technical capabilities of the HIE system are, a successful HIO requires a strong and supportive organization and coalition of stakeholders, users, staff, and other participants. In addition, meeting providers at their own technological level, supporting them along the technology adoption curve, and not requiring large investments or changes in the current health IT structure of the organization to participate in HIE further enhance the chances of success.

Establishing electronic health information exchange is highly complex because it demands advancement in multiple challenging areas in a synchronized manner: engaging stakeholders, establishing governance structure and practices, securing financing, designing the system's technical infrastructure, making the system operational from a business and technical standpoint, and developing policy. Based on the SRDs' experience, the success of future HIOs will depend on how they incorporate the following lessons into their own work:

- Engage a broad range of stakeholders in an advisory manner. Build trust among them and with the HIO, so that they continue to invest in the effort for the long term.
- Use formal and informal governance structures—including a board of directors and other advisory groups—to cultivate leaders for HIE in the community. Allow these governance structures to evolve over time.
- Develop plans to finance HIE early, make a compelling business case to participants, and set expectations for long-term sustainability.
- Understand that technical infrastructure will be shaped by policy and operational considerations, stakeholders, existing standards, and the capacity of vendors and participating organizations.
- Recruit a large user base; it is essential for making the HIE system operational.
- Understand that the operational costs and activities will be substantial. The needs and values of the HIE participants will evolve over time, and the HIO will need to respond to those changes.
- Realize that key policy decisions—such as the role of patient authorization in determining health information disclosure or exchange—can be influenced by Federal and State law and regulations, but may be shaped most by stakeholder considerations. These policy decisions will impact technical and business operations.

In addition to the key lessons learned in these areas, the SRDs also noted that developing health information exchange takes substantial time and effort. Although the SRD projects were originally projected to be completed in 2009, all but one have been extended through October 2010. This extra time has been required to understand the potential and complexity of HIE, as well as engage with stakeholders and develop the technical and policy infrastructure needed to support HIE.

As originally conceived, the SRD contracts focused on improving the quality and efficiency of care. However, as the SRDs began work and developed a greater understanding of the challenges associated with HIE, their focus shifted to accommodate the substantial challenges related to building a financially sustainable HIO. Throughout the process, the SRDs frequently

had to examine and revise their expectations for their activities, such as the timeline for building consensus among stakeholders, developing core policies, and conducting evaluations.

Over 5 years after the initiation of the SRD contract, the SRDs point out that understanding the true complexity of HIE—and its enormous potential to transform health care—takes a significant amount of time. The lessons learned reported here are just one effort that AHRQ is undertaking to make the SRDs' experiences known to others who may undertake similar initiatives to establish HIOs and HIE on a State or regional level, and thereby accelerate that learning curve for others in the future. Further review of the experiences of the SRDs and other successful HIOs will provide valuable information for new HIOs and HIO/HIE stakeholders.

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Appendix A. HIO Cost Considerations Template

The SRDs have identified costs associated with developing an HIO. These costs are categorized and listed in Table A-1. The SRDs noted that they tended to underestimate the magnitude of certain types of costs. They also pointed out that the magnitude of costs can vary depending on HIO policy decisions, contracted agreements, and Federal and State law and regulation. Personnel costs can be difficult to gauge since HIE is a relatively new area and there will be few experts who have the unique skills and experience required to implement HIE. Moreover, there may be costs associated with staff development, as new staff build their knowledge in the domains required for establishing HIE.

Table A-1. HIO cost considerations

Legal and policy
  Legal costs
  Intellectual property
  Liability insurance
  Policy development
  Financial management/accounting
  Marketing/communications
Central HIO personnel
  Organizational management
  Project management
  Staff development
  Staff relocation
  Fringe
Overhead/indirect
  Travel
  Phone
  Rent
  Space costs
  Organizational memberships
  Board expenses
Data center/hardware
  Servers
  Storage area network (SAN)
  Network attached storage (NAS)
  Network hardware
  Network connectivity (e.g., Internet Service Provider [ISP])
  Uninterruptible power supply (UPS)
  Server monitoring software

Table A-1. HIO cost considerations (continued)

Data center/hardware (continued)
- Data center security
- Security assessment/audit
- Data backup system
- Long-term storage costs (off site)
- Managed services
- System hosting
- Disaster recovery
- Server racks

Software
- Security software
- Clinical user authentication
- Intrusion detection software
- Firewall software
- Costs for custom development
- Doctor matching
- Patient matching: master patient index (MPI)/global patient index (GPI)
- Interface engine
- Database
- Clinical repository
- Record locator service
- Viewing application (Web portal or other)
- Electronic health record (EHR)/electronic medical record (EMR) software
- Common vocabulary engine
- Auditing software
- Standard interface tools
- Software upgrade costs
- Ongoing maintenance and support costs for all applications

Interface creation and maintenance
- Admission-discharge-transfer (ADT)
- Radiology interface: picture archive and communications systems (PACS)
- Laboratory interface
- Microbiology interface
- Blood bank
- Transcription

Table A-1. HIO cost considerations (continued)

Interface creation and maintenance (continued)
    Pharmacy
    Practice management/EMR/EHR
    Health Insurance Portability and Accountability Act of 1996 (HIPAA) transactions
    Claims
    Electrocardiogram (EKG)
    Continuity of Care Document (CCD)
    Continuity of Care Record (CCR)
    Other
Training/help desk
    End-user training
    Help desk costs
    Technical support costs
    Application administration

HIO=health information organization.

Appendix B. List of SRD Policies and Procedures

The SRDs identified the following policies and procedures that were relevant to establishing HIE in their States and regions. The SRDs report that it is vital to understand the interdependencies across different HIE policies, as well as between policies and other areas of HIE development such as technical infrastructure.

From their experiences, the SRDs recommended that HIOs think about the implications of each policy on the others, so that they can plan the sequence of their policy development accordingly. Tables B-1, B-2, and B-3 highlight three broad types of policies: those that codify policy in legal agreements (usually on an organization-to-organization level); those that address privacy and security (which would dictate operations); and those that address governance. One general example of a contingency that would be important to identify is how privacy and security policies would impact the content of legal agreements between organizations.

Some specific scenarios in which policies may be contingent on each other are:

- *Participation agreements* (see Table B-1) are needed when sources of health information for the HIE require that policies and procedures for *access logging and auditing, accounting of disclosures, breach notification*, and *data security* are in place (see Table B-2).
- Policies and procedures for *consumer enrollment* (see Table B-2) may not be able to be finalized unless other policies are adopted and can be communicated effectively to the consumer, such as *patient data control, emergency access,* and *redisclosure policies* (also Table B-2).
- The content of the *disaster recovery and business contingency plan* (see Table B-2) may depend on the technology selected and implemented for HIE at any time.

Many policies can be developed in parallel. However, the actual sequence in which an HIO develops policies may differ according to stakeholders' priorities, readiness to address the subject, or parallel technical model developments, to name some variables.

Table B-1. Legal agreements that define the boundaries of legal use of health information in a health information exchange

Appropriate use or data use agreement

Business associate agreement

Indemnification/termination/mediation of partners

Letters of intent or memorandum of understanding

Participation agreement

Confidentiality agreement or policy

Nondisclosure agreement

Table B-2. Policies and procedures related to ensuring privacy and securing patient health information within a defined health information exchange

Access logging and auditing procedures
Accounting of disclosures
Breach notifications
Data security procedures
Emergency access
Patient data control
Patient identification
Privacy practices
Provider matching
Redisclosure policy
User authentication
Consumer enrollment
Patient participation
Provider enrollment
Complaints and grievances
Disaster recovery/business contingency plan

Table B-3. Policies and procedures related to governing the health information exchange system

Defined voting rules
Governing principles and policies
Governance structure
Policy coordination
Reporting policies
Roles and responsibilities for committee members
Rules for adding members and their data
Subcontractor approval process
Agreement violations